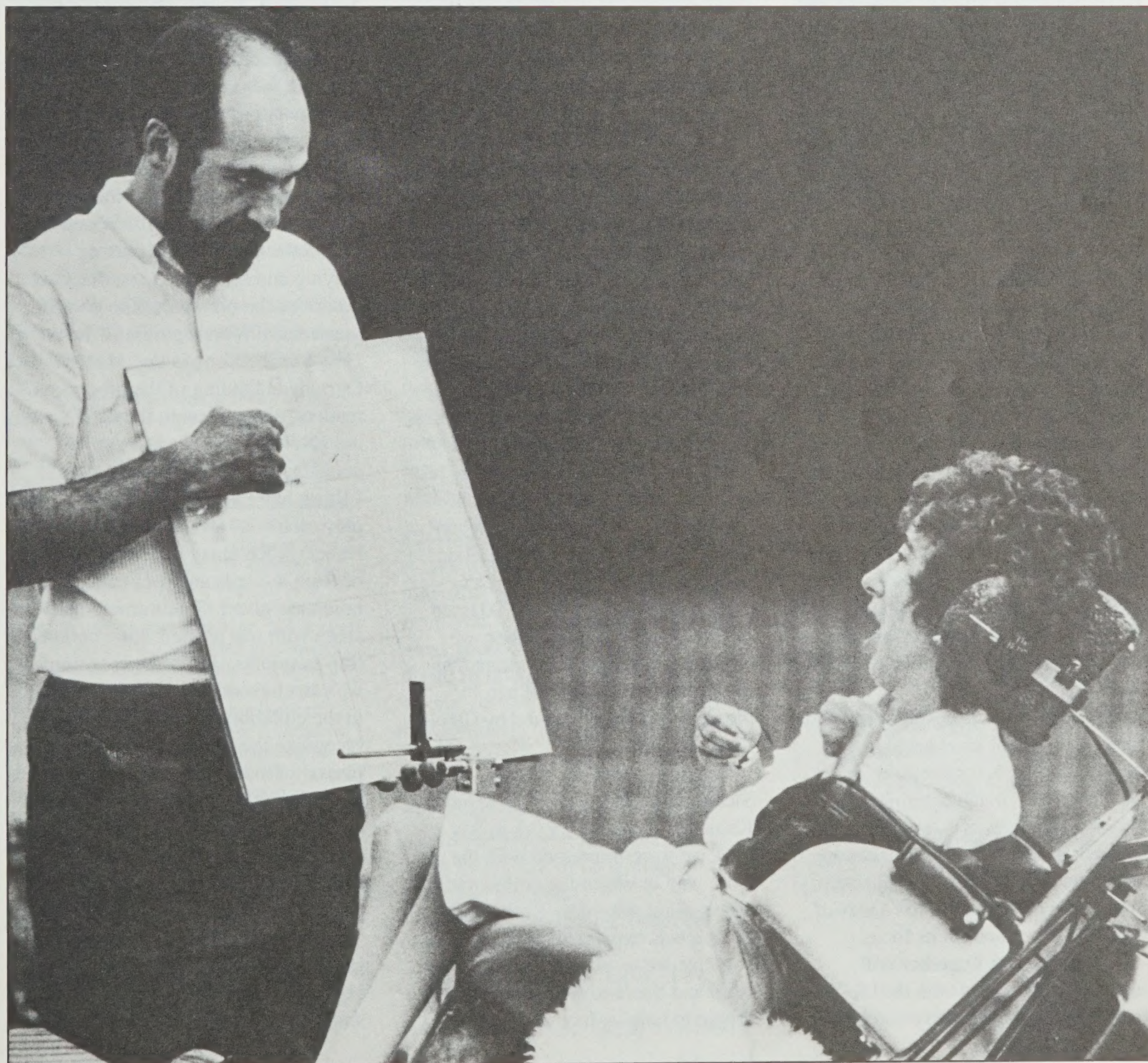


# COMMUNICATING TOGETHER

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A QUARTERLY MAGAZINE ABOUT AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

COMMUNICATING TOGETHER VOL. 9, NO. 3/SEPTEMBER 1991





SHIRLEY MCNAUGHTON  
PETER LINDSAY



When **Communicating Together** was established back in 1982, its mission was to provide a focus upon the human side of augmentative and alternative communication. Fulfilling this purpose is as important to-day as it was then and we are excited to be able to build upon the strong tradition established by **Communicating Together** during its first nine years. We thank Ann Kennedy, its managing editor, and the Easter Seal Society, Ontario for giving us this opportunity to maintain and to expand **Communicating Together's** unique role in the AAC world.

As we pursue the development and refinement of our knowledge in the clinical, research, service delivery, organizational, manufacturing and promotional areas of AAC, a magazine about and for people still has an important role to play. Specialization, with all its new insights, has a way of masking the reason for its focus. **Communicating Together** will always be concerned with the life situations of augmentative communi-

cators, presenting AAC issues as they affect users of augmentative communication systems.

We look forward to discussing many different topics in this editorial section. Next issue we will take a look at some of the pros and cons regarding *integration*. In the March, 1992 issue, *sexuality*-related items will be given attention. For this issue, the area relating to AAC users that has captured our interest is the nature of the collaborative process that is involved in writing with augmentative communicators.

## Collaborative writing

Two articles, published in earlier issues of **Communicating Together**, stimulated our thinking about what we originally thought of as "shared authorship". In the June, 1990 issue, an article entitled, "My First Encounter with Death" by John Dowling appeared. The introduction indicated that "John wrote" the article. However, John was quick to tell those of us who are familiar with independent writing skills that the "ideas" were his, but the "writing" was done by his good friend, Murray Spence. When Susan Odell responded with a letter, published in the "*Readers Write*" section of the September, 1990 issue of **Communicating Together**, we who knew her well, were aware that the written presentation of her thoughts had been prepared by Carol Lynn Katsios.

When we each read Ruth Sienkiewicz-Mercer's and Steven Kaplan's I Raise My Eyes to Say Yes, we were impressed with the up-front way in which the collaborative relationship shared by Ruth and Steven was explained. It is an example for us all and so we invited Ruth and Steve to write our feature article to help us focus upon this

topic.

We have discussed the process with several authors and learned more about the high level of skill that shared writing requires. We originally used the term "ghost writing" but Howard Shane suggested that we also consider "guided co-authorship". We began to realize that different writing relationships require different terminology and we have added "collaborative writing" and "independent writing supported by strong editing" as other ways to describe the process.

When does written work involve "ghost writing", when is it "guided co-authorship", when is it "collaborative writing", when is it independent writing with editing"? We need to know what role each partner is playing and select the term that best describes the process. Who contributes what? Who is guiding whom? How much editing is undertaken? Our understanding of the process as readers, depends upon the details we are given relating to each partner's contribution to the writing process. I Raise My Eyes to Say Yes is particularly informative in this respect since many direct examples of Ruth's words and Steven's translation are given. Their article here starts with one of their more compelling examples. From these examples we can envision what was involved in the collaborative process and recognize the role each partner has played. This is important learning for those interested in the empowerment of augmentative communicators! We are delighted Ruth and Steven agreed to share their experiences in working with each other in "Good Match - The Key to Collaborative Communication". For another sensitive description of co-authorship, we recommend Carol



Lynn Katsios' "Ghost Writing for Sue" in the *Perspectives* section.

Mike Boone, in his article, "Interpreting: The Development of the Profession", published in *Augmentative Communication* section of **Communicating Together**, December, 1990, made a distinction between the professional and the "helper". He described the professional as having a code of ethics that includes "confidentiality, impartiality, proficiency, discretion". Whether we apply the term "ghost writing", "guided co-authorship", "collaborative writing" or "independent writing with supportive editing", we hope that these qualities will be included within the roles of all speaking/writing partners - be they nonprofessional "helpers" or professionals. To Boone's descriptors, we would add - "provision of the appropriate support to achieve full empowerment for the augmentative communicator"!

Ruth Harrington reflects upon the flexibility that she has needed in her collaboration with her daughter Kari:

"It's different with almost every article - depending on the topic, the material available and Kari's knowledge of the subject. Sometimes there's a pooling of ideas to get a list of possibilities for a topic and then Kari chooses. Sometimes Kari does the whole thing herself, calling on me after it's finished. When we read it over, I may help her to reorganize her sentences into a better paragraph or a better sequence or suggest a different word to use. Sometimes Kari will accept my suggestion but she often prefers her own choice and sticks with it. This is true for every suggestion that I make. I might say, "Why don't you tell about..? She may or may not want to. I certainly feel she has the control! I help edit for grammar (especially for verb tenses) and for spelling. Sometimes Kari just writes a list of all the ideas she thinks would be good to mention and then we go to the computer together to write it with input from both of us - deciding together what to say next. Often, while we're doing this Kari comes up with some funny remark or quip and we put that in. Any humour that appears comes from her! (As I do the typing on this occasion, Kari is reminding me of how boring -lacking in humour- I am!)"

The challenge to each one of us who participates as a partner in the writing process is not unlike our role as facilitators for face-to-face communication. Howard Shane (personal correspondence, March 25, 1991) related the skills needed for guided co-authorship to those required to support the independent communication of persons using communication boards. We have to contribute as much assistance as is needed by the augmentative communicator and no more! Easier said than done! Facilitators must guard against creating an enforced dependency or expanding their roles to exaggerate the communicative capability of augmentative communicators. How easily this habit can be developed through guiding AAC users' hands or structuring their output beyond the level needed by the individual. Sometime in the future, as technology continues to develop ever greater capabilities to support the augmentative communicator, we may need an editorial relating to individuals maintaining their control and independence over the power of devices! Lots of challenges ahead! Here's to more sharing and more learning in future issues about partners in the writing process!

### Closing Comment

All of us who are putting this magazine together are eager to hear from you. We want to know your ideas about topics, what we are doing right and what we are doing wrong, material you would like to see published, themes you would like to see us explore, or articles you want to submit. We want to make this magazine as responsive as we can to the needs of the field. Please write to any one of us with your ideas and reactions:

c/o **Communicating Together**  
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Thornhill Ontario, CANADA,  
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Finally, we agreed to take over the editorship of this magazine because we believe it is important for the field. To survive, however, we must increase its circulation this year. Please support us by urging your colleagues to subscribe now to **Communicating Together**. We have included a subscription form for that purpose. Remind anyone who would like a review copy before they subscribe, to complete the reverse side of the subscription form or to give his or her name and address to one of the following manufacturers when visiting their displays at conferences in the Fall:

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Shirley and Peter

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## "GOOD MATCH": The Key To Collaborative Communication

RUTH SIENKIEWIECZ-MERCER  
STEVEN B. KAPLAN

"I FEEL (CLUE) TRASH  
BELCHERTOWN  
OLD HOUSE STINKS  
(CLUE) HOT  
BELCHERTOWN  
I GETTING FOOD MYSELF  
PLC. ASK ME WHAT WHEN  
PATIENTS MOVE OUT  
MONEY PEOPLE OUT  
BROKEN THEY BUILDING."

*These words are what Ruth Sienkiewicz-Mercer laboriously communicated to Steven Kaplan using eye gaze and an alphabet board to indicate her feelings about the Belchertown State School where she had spent 16 years of her life. At a rally to close the school Steven Kaplan, Ruth's collaborator on her autobiography, I Raise My Eyes to Say Yes, interpreted those words to the gathered crowd as follows*

"At the rally, I provided a brief description of Ruth's background and experiences at Belchertown. I then told the crowd, I asked Ruth what she wanted to say to this gathering and she had these comments: 'I was treated like garbage at Belchertown. The infirmary stunk and the whole place was like hell. Now I am getting an education. I go grocery shopping for myself, and my personal care attendants ask me what I want to do and when I want to do it.'

'All of the people still living at the State School should be moved out, and all of the money now being spent at the institution should be directed at the handicapped living in the community. The State School should be torn down brick by brick.'"

(p224-225)

*What is the nature of the process that goes on between the non-speaking individual and his or her "interpreter" so that the speaking partner knows what the non-speaker really means to say? How do we communicate the emphasis and feeling of the utterance in addition to its content? We found these questions so intriguing and important to the field of augmentative communication that we decided to ask Ruth and Steven to write about their experiences communicating together while they wrote the book about Ruth's life. What follows is their response.*

---

**"If I were granted  
one wish and one  
wish only, I would  
not hesitate for an  
instant to request  
that I be able to talk,  
if only for one day,  
or even one hour"**

**Ruth Sienkiewicz-Mercer**

---

In 1989, ten years of collaborative communication reached fruition with the publication of our book, **I Raise My Eyes to Say Yes**. The book tells the story of Ruth's life in a first-person narrative. Our book is a little different than the usual effort by the subject and an "assisting" writer, however, because Ruth is a lifelong quadriplegic and has never been able to speak or write. Ruth told her story to Steve by providing words, phrases and clues via word boards, and he in turn wrote her narrative and filled in details where necessary from records and information from Ruth's friends

and family members. The story and perspective were Ruth's, and she served as both original source and final editor, but most of the words and descriptions were provided by Steve.

**Steve:** Our collaboration on this project began in January 1979, when I started working with Ruth as a teacher in a small, individualized program for severely disabled adults in Amherst, Massachusetts. Ruth had recently left the Belchertown State School after sixteen years of unwanted institutionalization, and had moved into her own apartment, and life, in the community. Her experiences at Belchertown generally had been terrible and she wanted to tell the world about those experiences and the evils of institutionalizing and segregating disabled individuals.

One broad exception to Ruth's bad experiences at Belchertown was her development of a communication system, with the help of a number of talented and dedicated speech therapists and teachers who worked with her during her latter years at the institution. Building upon this work, by 1979 Ruth was using word boards with about 400 entries — names, phrases, places, verbs, adjectives, adverbs — arranged in groups to express her ideas and thoughts. Laura Lee Jones, another teacher, and I worked with Ruth to increase her "vocabulary" to about 800 entries. Since then, Ruth has enlarged her expressive repertoire to about 2000 entries on her words boards.

**Ruth:** To communicate with Steve (or anyone else) I use my word board as follows: My communication collaborator holds the boards in front of me, and I direct my "listener" by looking at a part of the board. The collaborator then points to rows and



columns of the chosen section of the board, and I guide the listener to my selection by raising my eyes to say “yes” and frowning to say “no”. I add emphasis and subjective commentary by my facial expressions and by about a dozen different vocal sounds.

**Steve:** As the listener in this dyad, the biggest challenge for me was to identify Ruth’s selections and then figure out what she meant by them. Some messages are relatively easy, such as “I.TIRED.” to mean it’s time for a rest. But that same pronouncement by Ruth might mean much more, such as she’s tired of dealing with a certain problem or person in a particular way and that she wants to take particular steps to change the agenda. The clear expression of that message might take hours, and might not always be fully successful.

**Ruth & Steve:** Our advice to anyone involved with any comparable type of communication process is best summarized by Ruth’s comment: “**.GOOD.MATCH.**”. The speaker and his or her collaborator must establish a good personal and working relationship in order to succeed. This not only requires basic compatibility, but also necessitates sensitivity and understanding of both the speaker’s and the listener’s objectives, a great deal of patience, and the development of mutual respect and friendship. Without all of these factors, it will be impossible to achieve the ultimate goal — to facilitate a broad expression of thoughts and ideas without subjective interference from the listener. In working together on our book, we succeeded on all of these levels. But that is not to say we didn’t encounter problems along the way.

**Ruth:** Probably the most difficult part for me was when I told Steve about my sexual desires and

frustrations from the Belchertown days. In the book, we discussed my sexual fantasies about a friend named Hans, a man who worked as a psychologist at the institution. Recently, I made the following comments to Steve from my word boards about these passages:

“BOB I EXPLAIN TO STEVE  
SIMILAR LITTLE MISTAKE IN  
BOOK. I SUGGEST SEX SIMI-  
LAR WOMEN HELP WRITE  
STEVE. I FELT FACE RED SEX  
A MAN TELL I ABOUT SEX”

The first comment stated that although my sexual fantasies were attributed in the book to Hans, I also had experienced similar thoughts about a man named Bob, a recrea-



tional therapist who worked with me. We had made a “little mistake” in the book by failing to mention this fact.

The second comment expressed my difficulty — which Steven and I understood at the time — in telling a man (Steve) about a woman’s sexual desires and frustrations. Understandably, my “face felt red” with embarrassment in revealing such intimate thoughts, but I overcame my modesty because I believed that the issue of sexuality for the disabled had to

be discussed honestly and realistically.

**Ruth & Steve:** We encountered other difficulties in writing the book, but the most significant problems all related to the same fundamental issue — honesty and realism in expressing the thoughts and desires of a disabled woman. Ruth went through much anguish with her parents and family by publicly revealing both her love for them and criticism of their decision to place and keep her at the state institution. But she also reached a deep and abiding understanding with her family over these issues because of the honesty and realism with which they finally addressed them.

Anyone involved in communicating with a person who cannot speak knows the frustration and rewards of the process. While most of the frustration involves one’s inability to say or write words, the truly profound rewards occur when the lack of words does not get in the way of clear and honest expression. Those moments are rare and precious.

*Before leaving the story of how Ruth and Steven communicated, let us close with another quote from the result of their communication - Ruth’s autobiography. In this extended quote, Steven spells out his own concerns about the interaction and his obvious admiration of Ruth for her communicative skills. The section is entitled “**How to write for Ruth**”.*

“The idioms and vocabulary, the tone, the nuances of language she would use if she could express herself on paper - all of this is a mystery that will never be resolved. Ruth talks through her eyes, facial expressions, grunts and sighs and other sounds, and selects two or three words/messages/fragments/clues from her



word boards to germinate the conversation.”

“But how does the voice in her mind speak? What words does it choose? I have posed these questions to Ruth. Her response is that yes, she thinks like everyone else, that her inner voice talks in words, and phrases, sentences, even paragraphs.”

“But does she think in words and phrases alone? Are her mental utterances like the speech she hears others speak or are they more akin to the shorthand speech she produces on her word boards. Do visual images figure more prominently than words in her internal dialogues? And what does her inner voice sound like? Since she has never spoken, does she perceive that inner voice as an extension of her own spirit? Or does she perceive it as some disembodied intelligence that drops by for frequent chats? Does that voice, Ruth’s inner voice,

speak in a flowing dialect of words, phrases, and sentences? Or is it assisted by internal sounds and evocative nonverbal images?” “This is a woman who has never walked or run, never jumped in the air, never clapped her hands or even scratched her face, a woman whose most prodigious self-propelled physical movement was rolling around on the living room carpet in childhood. Her most acute independently generated movement since then has been to stand semi-upright in her wheelchair for a few seconds. For this woman, thinking is the most active of verbs.”

“I don’t know how anyone else thinks but I wonder whether Ruth thinks like everyone else. How could she? How couldn’t she?” “For anyone who knows Ruth well, soliciting her thoughts poses no problems that time and patience won’t solve. She usually expresses herself quite clearly and

directly.

“This is a woman who has never spoken. This is a woman who has no choice but to choose words more carefully than anyone I have ever known. The limitations placed on her communicative faculties by her physical handicap have forced her to utilize an economy of language that eliminates most, if not all, of the trivial verbiage found in casual conversation. Communication is too precious a commodity for her to waste the attention of her audience on meaningless or misleading statements. She is clever and innovative in expression, yet always blunt. She uses conversation to reveal, not mask her thoughts. Ruth’s communication is in the most fundamental sense, pure poetry. By necessity, she speaks symbolically. Her every verbal utterance engages language at its most compressed, essential yet suggestive level.”

(p xii-xiii)

## COMMUNICATION OUTLOOK

### FOCUSING ON COMMUNICATION AIDS & TECHNIQUES

COMMUNICATION OUTLOOK is an international quarterly magazine which documents and celebrates augmentative and alternative communication. Our readers include communication aid users and their families, lawyers, manufacturers, rehabilitation engineers, speech/language pathologists and third-party payers.

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*May we suggest that Ruth and Steve’s collaborative writing is indeed “pure poetry”. Ruth’s “symbolic speech” has been captured and brought from its deep semantic base to an understandable, compelling narrative. Together they have met the challenge of every facilitator- non-speaker diad, to communicate not only the meaning of the message but also the personality and feelings of the individual involved.*

### Reference

Sienkiewicz-Mercer, R. & Kaplan, S.B.. (1989) I Raise My Eyes to Say Yes. Houghlon Mifflin Co., Boston.



CATHY FAIRLEY

The Paraphrase is written for those who are moving into traditional orthography. It offers an independent reading opportunity for the growing reader. The Paraphrase is written by Cathy Fairley, former consultant at the Easter Seal Communication Institute.

## School Integration that Works

I think my integration into school is a success. I think many things help integration to work.

Teachers must want to teach people who are disabled. When there are problems, they need other teachers who can give them lots of ideas. I have had many teachers who have helped me learn.

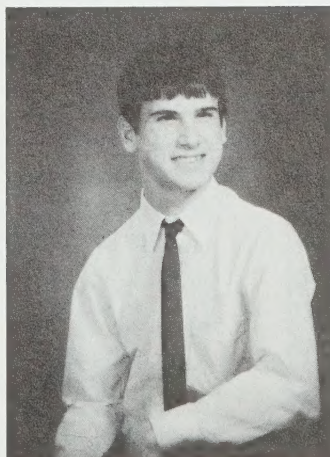
It is good to go to the school near my home. My classmates know me. They are my friends. They help me when I need help. Most of my classmates accept me. But if they say mean things to me, my parents say “in one ear and out the other”!

When there is a problem, we look for a solution. I have learned not to give up. We just keep trying.

People who are disabled must set school goals. I have worked hard to make integration a success.

I am happy to say that I am integrated in school. I am proud to say that I am integrated in life, too.

This article was originally written by Victor Valentic. It appeared in the last issue of **Communicating Together**, June 1991.





## Leaving Home

KARI & RUTH HARRINGTON



*Kari Harrington has been writing for **Communicating Together** since 1984. Her regular section has been enjoyed by readers since September, 1987. Kari was in the original Blissymbol class of 1971 at the Ontario Crippled Children's Centre. Through the years, she has used many forms of technology and has gradually assumed control and independence in all matters relating to her communication system. With the new **Communicating Together**, Kari's mother, Ruth, joins with Kari for some of the issues, to add her perspective to "Living".*

The move away from home can be an awesome and scary prospect for anyone, whether child or parent. For a few, their upbringing, education and life experiences have combined to give them the self-confidence to **know** they can make their own way and they welcome the opportunity to do just that. For others, the step is made with some trepidation. They recognize many of the challenges they will have to face, the responsibilities and the changes in life-style involved. They understand that, for one reason or another, the time has come for them to

make the move. They know they must gather the courage to face their fears and to work at solutions to the problems that will inevitably arise.

We will be sharing the "living" experiences of several special individuals in the next few issues. For some articles we will work together, and for others, one of us will do a solo. This column by Kari begins with one of her poems then tells the story of her search for a place of her own.

### Where Are The Answers

**I wish I had an answer  
For all my many woes.  
It seems I have a problem  
From my brain down to my toes.**

**I ask my many questions.  
They say, "Do not not despair."  
But where are all the answers?  
Where, oh where, oh where?**

I can't begin to tell you how many times over the years I have lain in bed and worried about my future. So many questions would pop into my mind: Where will I live when my parents can no longer look after me at home? Will people understand what I need? Who will look after all the equipment I use and make sure it gets repaired? Will there be someone to give me that little bit of help I need in order to do the fun things I like to do? After a very restless night, I would wake up and think again about all these concerns. No magic solutions would have worked themselves out in my brain in the short time of my sleep.

As I grew older, I often talked with my parents about my future and the possible living situations for me. We visited an apartment project and a group home in Toronto and discussed what we had seen and heard about each type of facility.

I cried myself to sleep several nights after our visits to those city

apartments! It wasn't the apartments themselves or the nice people who lived in them. It wasn't the thought of living by myself either. That was a scary thought, for sure, but it was more than that. I realize now that at that time, I mostly was frightened by the prospect of living in the heart of the city. It was a different world than the one I had grown up in. I had always lived in the same house in the old village of Markham. I knew the people and the community so well I could go around town and do the things I wished quite confidently.

At this stage in my life, I decided that Participation House (P.H.), a residence for up to thirty-six physically disabled adults, just ten minutes drive from my home here in Markham, was the place I wanted to be. My name had been put on the waiting list there even before the facility was built seven years before, with the hope that when I was an adult and ready to move from home, there would be a place for me. My mother and I went over to tell the director that we were looking seriously for a placement and when one was available, I would like to be considered for it.

I had made my choice. Now I must wait until a space became available, and even then, I knew my acceptance would depend upon my needs compared to the needs of all the others who were also on the very long waiting list. The Board of Admissions had to make that final decision.

That was step one. But there were other things to be considered besides a suitable place to live. I was twenty-three years old and I had finished High School. What was I going to do with all my time now? Thank goodness I still had my part time work as a presenter for the Easter Seal Communication Institute. Through that work, I had opportunities to meet new people



and to help others learn about augmentative or alternative communication. I also had my column to write for **Communicating Together** four times a year. Those jobs were only occasional things, though. I still like to write poems and stories, but I needed a reason to get out of the house each day, no matter which house it was.

My family and I discussed many things. More schooling was suggested. I felt I wanted a break from that. I think my hearing problems, along with all the others, made me feel that community college learning would be a real struggle for me. What would I do?

We knew that Participation House offered a life skills program, a workshop, an apartment readiness course and school. Thanks to the two teachers who work there, I could take correspondence courses on some of the high school subjects I had missed. We talked with the director of P.H. and it was decided I could go there every afternoon and take part in some of these activities. At least I would get out of the house each day; I would have the opportunity to socialize, and by traveling there and back on the Markham Mobility bus, I would get used to a public transportation system. It all worked out quite well for me and gave my mom a break that she needed very much right then.

Around the same time (the spring of 1989) several of the residents were moving out of P.H. into a newly completed and funded apartment project in the Town of Markham. This meant new residents could be accepted into the residence itself. I was considered, but turned down, because there were others in more need than me. In addition, some people on the Admissions Board didn't think P.H. was the best placement for me. At that time, I felt it *was* my best choice and that I could make it work out for me. I knew it was time for me to get on with my own life. Not being accepted at P.H. was a real disappointment both for me and my family.

However, it pushed me into changing my thinking about where I might want to live. When I was told there was another apartment project planned for Water Street, just five minutes from home, everything took on a new light. I could drive to and from it in my electric wheelchair. I knew help was close by if at first I had serious problems taking over the full responsibility for my own care. I began to convince myself that independent apartment living could be all right for me. I began taking the apartment readiness course that P.H. offered, and started to learn some of the things I needed to know in order to direct my own care. Getting one of those Water Street apartments became my goal.

Every cloud may have a silver lining, but the opposite can be true too. Just when I thought I could see my silver lining, two different clouds appeared. The first was that although the building of the apartment project on Water Street was progressing well, efforts to get government funding for the necessary support services for the disabled units were not. Instead of increasing spending on services, it was necessary to make cut backs. (For many months everyone was quite discouraged. Right now, there is a glimmer of hope again. Maybe by the time this story is actually printed in the magazine it will all be taken care of.)

During that discouraging period (the fall of 1990, and the early winter of 1991), a vacancy became available in the Participation House residence. I was asked if I wished to be considered for it or if I wanted to wait and see what would happen with the apartment funding. My family and I talked some more, but the choice was mine. I applied for the vacancy at P.H. with the understanding that if the apartments did become available, I would still be considered for one of them. "A bird in the hand...." Also, I would get used to living away from home in a more protected setting, before I had to assume many new responsibilities.

The second cloud I referred to, you

know about. (At least, if you read the previous issue of **Communicating Together**, i.e. Vol 9, No. 2 you do.) Just three days before I was to move into Participation House, I learned I had to have brain surgery. I lived at P.H. for two weeks, had the operation, was in hospital for a month, recuperated at home for a month, and now I have been back at P.H. for two weeks. I am still recuperating and haven't felt like doing too much. I need to fix up my corner of the world to look a little more homey and arrange more of my things so I can use them. Right now, my computers are still at home, and I go home to work on them.

The nurses and staff at Participation House are great to everyone. Anyone who isn't feeling well gets special attention for as long as they want or need it. Since I still have a lot of headaches, I'm probably getting more than my fair share.

In the next issue of **Communicating Together**, I will be looking at Participation House in more detail through the eyes of a resident who has lived there for seventeen years.

## Join ISAAC Now

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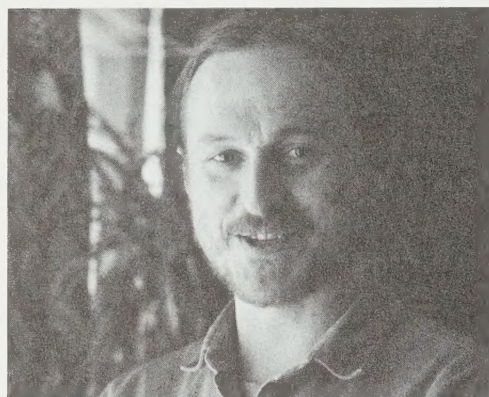
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## Consumer Awareness & Shareware

JEFF HIGGINBOTHAM



*Hello! My name is Jeff Higginbotham and I will be writing the "Consuming Technology" column for **Communicating Together**. I am a faculty member in the Department of Communicative Disorders and Sciences, at the State University of New York at Buffalo, and serve as the director of the Communication and Assistive Device Laboratory (CADL). A major goal of my laboratory is to study how people learn, use and interact with augmentative devices in order to create more accessible and powerful technologies. I am excited about writing this column as it gives me a chance to talk with consumers (e.g., clinicians, users, family members) about augmentative technology. I hope that this column will serve to (1) empower consumers of augmentative technologies through informative reviews about augmentative devices and software, (2) discuss issues regarding the rights and responsibilities of consumers of augmentative and computer technologies, and (3) present information about affordable ways for adapting your hi-tech devices to suit your individual needs. Future articles in this column will take a close look at speech synthesizers, word prediction programs and computer access technologies. This*

*time, however, I would like to talk a little about my thoughts about the "consumption" of computers and augmentative communication technologies.*

### Personal history

In addition to my professional work in the augmentative area, I have also spent the last 12 years working with microcomputers on a daily basis. In the beginning, I was intrigued by the glitz, power and promise of computer technology. But as I began to deal with their complexities, limitations and breakdowns, I realized that my computers were also *consuming me*. I find that when my computers work as they should, they make my life immeasurably easier and more productive. However, when they fail to work as advertised, or breakdown, the results are *time-consuming* and frequently *devastating* (I lost 500 telephone numbers and 6 months worth of appointments when my electronic organizer broke last week!) I chose the title of this column "Consuming Technology" to express the idea that as we consume new technology, it, in turn, consumes our money, time and energy. If we are going to make a commitment to a hi-tech life-style, we need to make sure that our technologies work for us, rather than us working for them.

### Car Dreams

In my opinion, one of the biggest problems facing consumers of augmentative technology has to do with shopping for and purchasing these devices. I'd like to tell you about a dream I had which illustrates this problem.

When my wife and I bought a new car recently, we found ourselves having to make a series of decisions about the purchase of this expensive product. I found the whole experience somewhat unsettling because of

the significant financial outlay, the abundance of new and different models from which to choose, the "assertiveness" of the salesperson, and a nagging feeling that we should have done a little more homework before making our decision. One night, shortly after purchasing our car, I had the following dream:

**Setting:** A dimly lit warehouse filled with cars. Fog billows up from the ground. A car salesman, dressed in polyester, and smelling like stale cigars approaches my wife and me.. like a lion stalking its prey.

**Salesman:** Yesseree, I can give you a good price for this beautiful model.

**Me:** I see that the engine is a 429 cubic inch V8 (adolescent fantasy). What kind of gas mileage does it get?

**Salesman:** Great mileage kid; depending on the driving conditions you can get up to 75 miles to the gallon (on the moon). And the tires are rated for 100,000 miles. Also, the new spider-web passenger protection system is designed to keep the kids in the rear of the car during an accident. Our research has shown that the driver should have his hands free for driving during an accident. Of course you know that you can't return the car or trade it in for the next 5 years.....

(At this point in the dream, I awoke and sat straight up bed, nauseous and shaking like a leaf).

Although a bit bizarre perhaps, I think that my dream highlights some of the significant problems faced by consumers shopping for augmentative technologies. First, because there is relatively little reliable information available describing the features or performance capabilities of augmentative technologies, in many parts of the world, consumers are ultimately dependent on sales representatives and manufacturers for information about their products.



Consumers shouldn't have to rely only on their own experiences or on information provided by the people selling them the product. When shopping for a car, consumers at least have things like EPA gas mileage estimates, in-depth performance reviews as well as repair records researched by independent consumer groups.

It is also difficult to "test drive" many of these products, due to their limited availability or their purchase requirements. The net result is that consumers are frequently forced to purchase a device before they've tried out enough products to see which ones are most suitable for them. It should be noted that at this time, well over 100 different augmentative communication technologies are currently available, making the job of "test-driving" even a reasonable sample of these products difficult at best. And if the purchased communication technology doesn't work as planned (due to the unavailability of in-depth product information and adequate testing), many individuals are saddled with having to use a less than fully functional technology for long periods of time, due to restrictions tied to many third party purchase plans.

I think these problems are quite serious for augmentative technology consumers, especially since we are dealing with people's self sufficiency, self concept and quality of life. If we are to solve the problems mentioned above, we need better access to product information. We need augmentative technology reviews that are comprehensive, comparative, objective and address the consumer's point of view. I encourage all consumers to talk to your clinicians, advocacy groups, USAAC and ISAAC to find ways of dealing with these problems. Ensuring appropriate access to technology for everyone is possible, but we have to take the initiative now!

## Shareware

One small solution to providing access to computer technology is to make the software programs free or relatively inexpensive. Shareware provides such a solution. These programs can be purchased by writing to their authors, or they can be obtained from computer bulletin boards or information networks like Compuserve. I would like to share with you some of my favorite programs and utilities to make the Macintosh computer accessible to everyone (I will talk about IBM and Apple II products in later columns). The following programs range from being free to under \$50US. Most of these programs can be downloaded from Compuserve Information Service (CIS) or America Online (AO) which allow you to try before you buy. Most of these programs also appear to be compatible with Apple's new System 7.0:

**Automenus 4.0:** Allows you to select menus and items on the the Mac screen by pausing on any item (i.e. you don't have to click the mouse)! Michael J. Conrad, 955 Escalon Ave #505 Sunnyvale, CA, USA. 94086/\$10. Also located on CIS and AO.

**TypeIt4Me:** An abbreviation-expansion utility for the Mac for encoding frequently used words or phrases. Works with any word processing program. Riccardo Ettore, 67 rue de la limite, 1970 W-Oppem, Belgium. \$30US money order. Also on CIS and AO

**Commander v1.2:** Commander allows you to assign or change the command key settings of almost any menu on your Macintosh. John Stephen. Located on CIS and AO.

**OpenWide version 2.2:** The program enlarges the standard file dialog box (e.g., open, close) to allow more files and longer names to be seen by the user. System 7.0 compatible. A very nice utility! James W. Walker, 3200 Heyward Street, Columbia, SC, USA, 29205. Send

him a postcard of where you live. Also on CIS and AO.

**Speed Chopper:** Slows down the Macintosh from 10 - 90%. Useful for games with moving targets. From: Seagull Engineering, Sweden. Located on CIS and AO.

**Scroll Limit:** Helps you control the speed and responsiveness of the scroll bars on the Mac. Blue Cloud Software. Located on CIS and AO.

**Easy Access:** Apple Computer's incredible system software which allows you to control many features of the keyboard including the key acceptance time, turning off the "autorepeat" feature, permitting "keylatching" so that keys that usually need to be pressed simultaneously can be pressed in sequence, and finally, allowing the mouse to be controlled completely from the keyboard. From Apple Computer Inc. Part of the Systems 6 & 7 software.

For further information relating to *Compuserve Information Service* (CIS), contact:

Compuserve Customer Service, P.O. Box 20212, Columbus, OH 43220, USA.  
1-800-848-8990 (USA)  
1-614-457-0802 (Canada)

To contact *America Online* (AO):  
America Online,  
8619 Westwood Center Drive,  
Vienna, Virginia, 22182 USA  
1-800-227-6364 (USA)  
1-703-893-6288 (Canada)



## A Clinician's and a Consumer's Perspective

COLLEEN MCGAFFEY & ROB HAAF, NOLA MILLEN



*Well, while Rob and Colleen are thinking of a way to introduce our column, I might as well do it. (They're sitting on the floor of my apartment, deliberating with no end in sight!)*

*We hope that you will enjoy reading "Teaching and Learning". Each one of us brings a unique perspective to this effort. As a speech pathologist working with children and adults with multiply handicapping conditions, often in the school setting, Rob will bring a clinician's perspective to educational issues. Colleen is an instructor who provides computer-aided learning activities to children and adults with developmental and physically handicapping conditions, and she will also bring a unique clinical perspective to these articles.*

*Last but not least, I am a university student with a Bachelor's degree in Psychology, currently working on an Honours B.A. in English and Creative Writing. I communicate using a word board and VOCA, and write using a typewriter (and, hopefully, a computer very soon!). I will be bringing the consumer's perspective to all of our articles, by writing about my experiences, and contributing to anything Rob and Colleen manage to come up*

*with on their own. Why don't we see if they have anything yet?*

*(Thanks, Nola! That's just the introduction we were looking for! It should be very clear that we wouldn't have made it this far without your help. We'll take it for a while, so that we can talk about what we call...)*

### The Role of the Clinician in the Classroom

The educational setting is one where many concerns have to be addressed, since it is here that the needs of AAC consumers, their families, educators and clinicians regularly interact (and, on occasion, collide). The rest of this "inaugural" article is devoted to an overview of some clinical issues related to education followed by the perspective of a consumer on some of these matters.

In presenting the clinician's perspective on the (sometimes conflicting) goals and plans that revolve around an AAC consumer in the classroom, we should begin by looking at the assessment process. It's now recognized by many AAC professionals that an atmosphere of ongoing collaboration with care providers is the most desirable situation to establish at the outset. All those involved with a

consumer (including family, teachers, classroom assistants, resource teachers, etc.) have valuable information to contribute to the assessment process. The information provided by consumers, teachers and caregivers regarding the communicative demands of day-to-day activities should be as valued as the technical training and general strategies contributed by the clinician. In turn, if the communication system is to be truly functional, it needs to be designed for and its use trained in those day-to-day settings where it is to be used and where communication is treated as a necessary and valued skill.

As obvious as the above statements may be, a fundamental question has to be asked: How well does the "typical" AAC assessment promote such a collaborative and cooperative atmosphere? In our experience, it is often quite difficult to overcome the perception that clinicians are arriving in the classroom to provide the complete communication "solution" for the consumer. Given the medical model still so prevalent in AAC service delivery systems, the process seems to be that consumers are referred to clinicians who prescribe communication aids. Usually there is a significant waiting period during which little input regarding communication is available. Is it really any wonder that some educators and consumers view communication as the sole "job" of the clinician, and have difficulty accepting that their input is vital to the selection and establishment of an appropriate communication system? Clinicians can often be perceived as entering the classroom prepared to "teach" rather than to establish a co-operative working relationship with the teacher. We've observed that this image is a difficult one to overcome, and often is not consistent with the goals and time demands of the classroom. For



example, after spending hours discussing communication strategies at mealtimes, choice-making and social interaction in the classroom, one of us has been asked politely by teachers why we aren't "taking Mary out for speech"! (Sound familiar?)

This situation is further complicated by the introduction of technology. Ideally, the AAC clinicians should be able to create a compatible relationship between the individual and the technology, provide comprehensive facilitator training, and offer ongoing technical support and feedback to the consumer and facilitators. The time and effort required when technology is introduced however can be overwhelming for both the clinical team and the educators involved. In one classroom, it was observed that the introduction of a computer system led the teacher to nearly abandon many wonderfully appropriate activities (with switch adapted toys and games, co-operative meal preparation, and so on), first to learn the computer and then to devote a large amount of student time to solitary computer activities.

The introduction of technology can lead to unrealistic expectations on the part of service providers that a specific device will provide the complete solution to all communication problems. The onus is on the technology to allow the consumer to begin quickly to participate in many situations. It has been our experience that as the true role of the technology becomes clear, disillusionment can set in. While we have all had experiences where technology has simplified an otherwise overwhelming task, many AAC clinicians and educators have also had experiences where technology initially complicates an apparently simple task. One example is in training a consumer and school staff to set up, troubleshoot and operate a computer system that might allow the consumer to spell a few simple words independently. It is the responsibility of the AAC

clinician to introduce technical aids in a realistic manner that is consistent with the needs of everyone involved.

On the other hand, technology can indeed provide a measure of independence for people with handicapping conditions, and the evolution of technology is progressing rapidly. As clinicians, however, we must continue to consider the perpetual growth of the individual as well as the technology. To provide suitable matches between people and technology, and to monitor the system effectively so it is changed as often as necessary, is a prodigious feat for consumers, clinicians and teachers. Yet it is a feat that must be done.

### **The Consumer's Perspective**

(Gee, they're finally giving me a chance to share my ideas! See, clinicians don't REALLY want us to communicate; they just say they do!)

As a consumer, there have been many times when I have needed changes to the form of service and/or technology being provided by clinicians. They have had to be aware of my changing needs as I matured and developed. Though needs change, consumers of every age have certain expectations of the service providers to meet their ongoing needs.

When I was a child, I expected my therapists to communicate with my parents and teachers. When a clinician knew that there was something special going on, then he or she would offer ideas that were practical and sensitive to my needs. It usually meant a diversion in my classroom activities and therapy sessions to spend time to give me the capabilities needed to participate in the special event. Whether it was getting me to use a communication device to say "Happy Birthday" or to say a few lines in a class play, the therapist had helped me to interact with others.

As a teenager, I placed different demands on my therapists, but I had the same expectations of their services. I expected to have a say in which

devices I used. Now I was the one who informed my therapist that a device needed updating. When my therapists saw that I was accelerating academically they were sensitive to my need to concentrate on my studies, so they gave me the option of discontinuing regular therapy. My therapists supported my decision to remain in class, while reassuring me that I was welcome to go with them whenever a problem arose.

While clinicians have certain expectations of the consumer, consumers have their own expectations of clinicians. As a consumer, I feel that the three most important expectations are sensitivity, practicality and reliability. I want clinicians to be sensitive to my age and specific interests; clinicians should also be practical when providing the specified communication device or service. Finally, I expect the clinician(s) to be reliable in providing the assistance I need in learning and operating a device. Besides the product, I expect to receive training and ongoing follow-up when problems arise. When a therapist meets these expectations, then a genuine process of communication can begin to occur.

While we have had experiences in the classroom both as a teacher and as a student that have made us aware of many educational issues, we want the *Teaching and Learning* section to belong to the educators and consumers who read it. Our primary purpose in writing this column is to provide teachers and students with a platform to share their experiences, ideas, opinions and anecdotes. We hope to do this through articles by teachers and clinicians involved with AAC service delivery, and recollections of consumers who have experienced (and survived!) the educational system and have unique insights to share. We want you to consider this an open invitation to write to us with all of your ideas. This is your space; let us help you use it!



## Context: "Milieu, environment, whole picture"

GEB VERBURG



**Communicating Together** or "**ComTog**" as we affectionately think of it, is changing, striking out in wider and, as you have seen from the editorial sections, a more general AAC orientation. **ComTog** remains committed to providing basic information to people involved in the field of Augmentative and Alternative Communication: Information about technologies, high and low, practices, services, methods and means. **ComTog** will retain a soft spot for graphic communication systems; that is in its blood. Your magazine will become more family and user oriented, and, in the process, I believe that we will become both heavier (as in tackling tougher issues) and lighter (as in introducing more levity, comics, fun!).

Before explaining where the new column-head - CONTEXTS - comes from and how the column will incorporate consumer input I have some old business to attend to and some heartfelt thank you's to address. Let me begin with the thank you's.

### Thank You

Thank you Ann Kennedy, for supporting me, for letting me write about things that I felt mattered. Thank you for nurturing **ComTog** through its

second period of five years. This year will see **ComTog** reach the ripe old age of one whole decade. Thank you very much for your steadying and sustaining contributions.

Thank you Easter Seal Society of Ontario for financially supporting the magazine. You too have done your part for the magazine which now embarks on its first solo flight.

Finally thank you to all ESCI staff who over the years have contributed, editorially and practically. Thanks to you all.

### Empowerment Update

In the previous issue I wrote about empowerment, life satisfaction, and life in the 21st century. In the months since the writing of that column I came across several articles that dealt with these topics. Here is a brief review.

In the Winter issue of Rehabilitation Digest, David Logan (1991) presents his vision of rehabilitation in the 21st century. Logan raises a point that tends to be forgotten (or ignored, or suppressed) by professional AAC/rehab personnel. He argues that disability can be "defeated". That is, he believes that, like polio, disability can be eradicated. For people who were born with disabilities and for professionals who have seen the ill effects of false hopes, this position is not easily adopted. Personally I would love to believe in it but cannot yet. One might counter that an increasing proportion of disabilities are due to accidents. True. Accidents, however, are not random, unpredictable events. According to Francescutti and colleagues (1991), accidents too can be prevented. Accidents happen in quite predictable places, to people of known age and gender groups, often under preventable circumstances (when we are tired, worried, sleepy, careless, or forgot to buckle up, etc.). To the extent that we know about accident proneness and probability we can do a

much better job preventing accidents and their resulting disabilities. Even in the most optimistic scenario however, I still see the number of persons who need AAC and rehabilitation technology increasing whether through advancing age, or through advancements in life-maintaining medical procedures. I also know that AAC and rehabilitation technology as it stands today have quite a way to go to meet existing needs satisfactorily.

Of other points made by Logan, I found the following the most telling and powerful statement: "... in all our planning we will not accept anything which is viewed as special and therefore separable" (p. 10). AAC devices are still particularly conspicuous: they stand out, or even, stick out. It would be interesting to visit ex-AAC device users and ask them what their reasons were for discontinuing the use of a particular AAC device. I wonder how many ex-AAC users there are. What were their reasons for abandoning the technology? What were the alternatives from which they chose?

The above questions have to do with another cluster of as yet untested preconceptions (mine). Like mobility, communication is such a basic skill that, in my opinion, relatively few people who need an AAC device have the option to communicate without the device. A problem is that because AAC devices can be so captivating to AAC users, they may foster a dependency on the part of the user. This dependency in turn may prevent the user from objectively evaluating the device which is so crucial to the person's existence. We must actively seek out the people who will be able (dare) to criticize the technology. In an article about empowerment, Mick Joyce, an AAC user, spoke about giving power to AAC users in order to "put them on a parity level with the professionals" (Joyce, 1991). Perhaps



with such power, AAC users in the future will dare to criticize the technology.

Logan appears to be quite optimistic about the removal of special appearances. He believes that, in the 21st Century, the diversity of provision for people with special needs will be an integral part of the spectrum of services available for the population as a whole. This supportive environment will come about, in part, through the increase in the power of consumers of rehab/AAC devices. The sharing of information, solutions and technology will lead to a globalization of service options.

I offer two final pieces of advice from Logan. First, professionals and device users should change employment goals for their clients or themselves respectively. Secondly, persons with disabilities should develop a vision of technology. Employment goals should and, according to Logan, can be set much higher than they have in the past. Not every job held by a person with an academic degree requires a high degree of verbal facility. Most jobs require a high level of facility with linguistic, graphic, or computational symbols. Technology is getting better at providing access to those media.

### Life satisfaction

As an amplification of the discussion of life satisfaction ratings in the previous issue (**Communicating Together**, Vol 9 No 2), I want to point to an article by Kathryn Boschen (1990). Dr. Boschen provides additional data about differences between ratings by people with spinal cord injuries (SCI) and people without such injuries. People with SCI gave lower ratings to questions about Quality of Life (QoL) and locus of control, but rated satisfaction with residence conditions the same as non-disabled persons. An interesting difference between the two subject groups was that persons with SCI expected their

QoL to increase while non-disabled persons foresaw their QoL to decrease over the next two years.

### CONTEXTS

Those of you who have read this column in the past may remember that it was called "Service and Research" in the very beginning. The title was adapted to "Research and Publications" when it became apparent that I was writing less about service than about books or papers. But even that column name was appropriate only 1 out of 4 times. What I wrote about were issues that I felt were important for AAC device-users, consumers or service providers. I have written about research, advocacy, independence, attitudes, employment, technology, education, mobility, future construction, robotics, and about symbol selection, graphics systems database, and, my abiding hobby-horse, the ability of children to select (grow) their own vocabularies. I would like to continue to write about these kinds of things but share this writing process more with parents, device users and colleagues.

Thus, when the editors and associate editors of the new **ComTog** met in the beautiful surroundings of Niagara on the Lake, and I was asked what I wanted to write about, I said the same thing. That was relatively easy. The difficult part was to find a title for this column. How does what I write about connect to AAC? Or does it? I

believe it does, although it is never directly in the centre of AAC current affairs. To me there is always tremendous attraction in and around the edges of things, in the surroundings, in the linkages with other disciplines, other spheres of activity, future demands, and expectations. First and foremost, I am a psychologist interested in the development of children and young adults, especially their cognitive development. So for me, communication, mobility, and technology are always subservient to the goal of optimal development of the person as a whole. That interest inspires all of my work and most of my writing.

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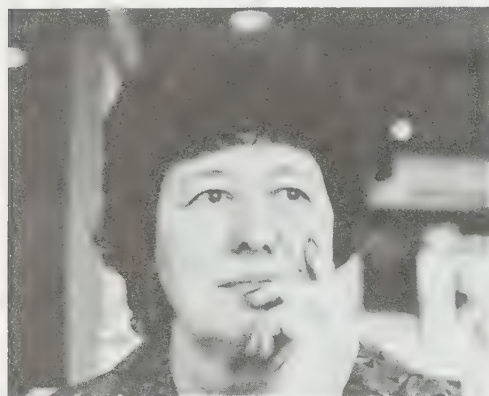
As the deadline approaches for the submission of presentations to the 1992 ISAAC Biennial Conference in Philadelphia, the ISAAC Consumer Committee and the ISAAC Conference Committee would like to encourage all interested consumers to consider submitting papers for presentation and to attend the conference. The Biennial Conference offers a most unique opportunity for consumers of augmentative communication, family members, educators, clinicians and others from across the globe to meet, converse, learn and have fun together. In addition, the ISAAC Conference affords opportunities to provide feedback and suggestions to the manufacturers of AAC equipment; to see and hear the latest technology; to communicate your ideas, feelings and needs to researchers, developers, clinicians and educators working in the field; to attend presentations delivered by consumers and professionals; and finally to establish international friendships and support systems. Hope to see you there.

**The ISAAC Consumer Committee**



## Ghost Writing For Sue

CAROL LYNN KATSIOS



When Susan Odell came into contact with an article in the June, 1990 issue of **Communicating Together** (Vol 8 No 2), she felt a need to respond. John Dowling's article, *My First Encounter with Death*, was something Sue could easily relate to. She had experienced death several times in her life, and was well acquainted with the frustrations the death of loved ones can bring to nonspeaking physically disabled persons.

Susan Odell was born with cerebral palsy, and communicates with a Blissymbol board that contains a vocabulary of almost 1000 symbols.

I agreed to "ghost-write" an article for Sue so she could express the feelings and frustrations she had encountered with death through the years.

When I first told Sue I would ghost-write for her, it had seemed so easy. Sue would just let me know what she wanted to say, and I would take notes, and write them into an article.

But the more I thought about it, the more I began to realize how difficult it would be to put someone else's feelings into writing.

I would have to experience another person's fears, tears, and anger from her perspective. I would have to try to see and hear things through different eyes and ears, and to relate to emotions

in a way that was different than my own way.

The feelings conveyed in the article had to be Sue's genuine feelings, not my interpretation of what she felt, or worse, what I thought she *should* feel.

Because I knew Sue, I knew a fair amount about some of the incidents she was going to discuss with me. As a writer, I immediately had some ideas on how I would like to write the article, the points I would like to bring out to induce awareness in readers; the ways I would like to phrase things; the emotions I would like to make visible.

My initial visit to Sue's apartment lasted several hours. The "good" hand that Sue uses to point to her Blissymbols is spastic, making communication for her a slow and tedious process. To compensate, Sue tends to say what needs to be said in as few words as possible. Much of my time was used just "drawing Sue out".

For example, how did she feel when the nurse said something or other to her? How did she react when people treated her in a certain way? What did she do when people ignored her feelings?

I later asked Sue if she had found it difficult to share her experience with me.

"I often did not have the words on my board to say the things I wanted to express," lamented Sue. "Because you knew me, you were familiar with some of the experiences I was talking about, so you were able to help me with words when I was stuck."

Much of what I said for Sue was paraphrased, and it is that aspect of ghost-writing for a nonspeaking person that is difficult. I must be able to capture effectively Sue's thoughts and feelings in sentences, even though they have been conveyed to me in precise, sometimes disjointed, words. It requires a lot of mutual trust, patience, thought, and understanding.

There were some difficult times. There were times when Sue would flounder half-way through a sentence for lack of words to continue expressing the thought she had started. But often by then I knew what she was trying to express, and she just needed some assistance to get words together. At such times, it would be possible for me say, "I'm going to put together a sentence, Sue, and you tell me if that is what you were attempting to say." But how do I know that is what she really would have said if I hadn't prompted her? How difficult this interaction would have been for Sue had it not been someone who knew her well!

As Sue's story unfolded, I found I was becoming quite emotionally involved. I was experiencing Sue's anger as my own as we painstakingly went over each detail of some very traumatic experiences in Sue's life. I was offended that anyone would be subjected to such uncaring treatment by others. But I knew it was necessary to share Sue's feelings, rather than just hear a story told. Sue's anger and bitterness were directed, not towards her disability or her circumstances, but towards a society that refused to acknowledge her as an equal human being.

I took notes on what Sue said, my impressions of the words and emotions involved, and verbatim quotes that I might want to use.

At home, I spent a lot of time studying the notes, remembering how Sue said things, imagining I was Sue when the incidents were occurring.

I tried to "hear" Sue speaking. How would she sound if she was saying verbally what she communicated to me on her board? What were her predominant emotions while relating events to me - not just words, but body language and facial expressions?

Finally, I tried to write an article that Sue would have written, not one that I would have written.



I made a second visit to Sue's apartment the following week so she could revise the manuscript. We spent a couple of hours going over it, and making notes for changes.

At home again, I rewrote the article with the necessary changes, and then made a third visit to Sue's apartment to make sure it was now what she wanted.

The next day, I handed the article to my editor, and "Encountering Death From a Disabled Perspective" was published in the September, 1990 issue of **Communicating Together**.

Sue had been anxious to write her article partly to express her feelings, and partly to create an awareness in others of how difficult some situations can be for nonspeaking disabled persons.

I asked Sue if it had been emotionally difficult to talk about such traumatic past experiences.

"Just the opposite," replied Sue adamantly. "It helps me to talk about it. Even though (husband) Art's death was 14 years ago, I remember it as if it were yesterday. Because I am nonspeaking, I get very few opportunities to have real conversations. It helps me feel so much better to be able to express my feelings about how much I still miss him."

I was reminded once again of something I had been made aware of many times, but which can never be restated too often - never assume.

The article Sue wrote bore little resemblance to the one I carried in my mind when we first began our project. The things I thought Sue would say were not the things Sue said. The points I thought Sue would make were the not the points she made. I realized once more how important it is to take the time to let a person speak for him/herself.

What about my self-doubts and fears at the beginning of our project? Had I accomplished what I had attempted to do? "When you read the article to me, it sounded exactly as if I had written it myself," said Sue.

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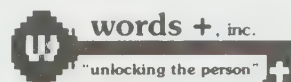
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## Science, Dignity and Opportunity

SHIRLEY MCNAUGHTON

*Shirley McNaughton has been associated with Blissymbolics and has had an interest in graphic symbol representational systems since 1971. Having worked as a teacher, consultant, lecturer and administrator, she retired from the position of Executive Director of the Easter Seal Communication Institute and Blissymbolics Communication International in 1989. She is currently involved in a doctoral program in the Department of Instruction and Special Education, the Ontario Institute for Studies in Education, University of Toronto, where her focus is upon the processing of graphic symbols.*

Let me introduce *SymbolTalk*! It will be appearing each issue, as an offspring of *Blissymbol Talk*. Why the change from a section dealing only with Blissymbolics? Quite simply, we want a broader as well as a sharper view that focusses upon the many types of symbols used in Augmentative and Alternative Communication (AAC). I hope *SymbolTalk* will allow us to use both wide-angle and telescopic lenses as we ask questions and share our learnings.

As the original publisher of **Communicating Together**, it was fitting for the Blissymbolics Communication Institute - now Blissymbolics Communication International (BCI)- to devote a section to Blissymbolics. The Easter Seal Communication Institute carried on this tradition during its years of publishing **Communicating Together**. Along with Claudia Wood, I happily contributed many Blissymbol Talk articles throughout the eighties. With the transfer of publication responsibility to **Sharing to Learn Inc.**, Peter Lindsay and I, along with

our team of associate editors, are extending the mandate for this section. We do so comfortably, knowing that BCI is now publishing *BlissWorld*<sup>1</sup>, a newsletter for Blissymbol users and their friends.

*SymbolTalk* will examine the role of symbols in augmentative and alternative communication, discuss the factors that are being identified as important, introduce new symbol sets and systems, identify questions that need to be asked and share answers as they are found. Underlying each *SymbolTalk* will be an interest in the benefits and the costs to users of different types of symbols.

### The Early Years and Now

In the late sixties and beginning seventies, catalogues and magazines were the sources for communication board pictures. Clinicians, teachers and parents found the search for "just the right" picture to be time consuming and students were dependent upon the perseverance of those around them for relevant *symbols* to represent their vocabulary. Today, there are many picture sets or systems designed for augmentative communicators; there are numerous texts, articles and software programs pertaining to symbols, vocabulary selection and display organization; and there is a body of research relating to the characteristics of different symbol types.

Yet, in spite of the wealth of information available, one can question whether professionals are any better equipped than they were in 1970 to really look at and evaluate the symbols they introduce to individuals. Rarely do I meet a professional who can provide a rationale for the choice he or she has made, beyond, "We introduced symbols that could be learned quickly by the user and that required minimal training by the teacher, therapist or family" or "The augmentative communicator liked

them". Little is known of the long term effect of the particular symbols upon the development of language and communication competencies. Rarely are linguistic, cognitive, and social considerations explained and an informed choice offered to individuals or their families. And although professionals recognize that many AAC users have difficulty in learning to read, seldom is the individual's first expressive communication system considered as a contributing factor in approaching literacy. We have much to learn!

### The Importance of Symbols

In 1980, the American Speech-Language-Hearing Association identified the symbol representational system as one of the three key components of an individual's AAC system (the other two components were technique and interactive behaviour). During the seventies and eighties many different types of graphic sets and systems were developed and made commercially available and new manual signing systems were introduced to augmentative communicators. Research attention to the different types of symbol representation used in AAC began in the eighties and is growing. Issues such as the iconicity and complexity of symbols began to be studied. These pioneering research projects are being followed by questions about the cognitive and learning requirements of various encoding and language representational systems (Beukelman, 1991; Light & Lindsay, 1991, McNaughton, 1990). A Think Tank planned for October, 1991 at Purdue University promises new insights, as professionals from Canada, Sweden, The Netherlands, United Kingdom, USA, discuss AAC graphics from a variety of perspectives - seeking answers to the many unresolved questions, along with raising new ones. Peter Lindsay and I have been invited



to attend and we look forward to participating in what we know will be lively and challenging discussion. We will be presenting a paper which will explore the role of symbols in providing the scaffolding for literacy development. We expect this to emerge as a dominant issue in the nineties.

### One Perspective

For this beginning article, I wish to share a perspective that served as the theme for the Canadian Congress on Rehabilitation, held in Charlottetown, Prince Edward Island, May, 1991. The title of the conference was Science, Dignity, Opportunity: Entering the Nineties. Although R. Lee Kirby, M.D. was referring to the rehabilitation process in his keynote address, I found it useful and easy to adapt his remarks and apply them to symbols.

### Science

The importance of our need for more science in the area of AAC symbol use cannot be overemphasized! We are just in the beginning stages - still searching for the right questions. Hypotheses relating to the features of graphic symbols that appear to be relevant to augmentative communicators' communication competency and literacy achievement is critical. An important information source, to provide impetus for research in this direction, is improved documentation of the progress of individuals, along with detailed descriptive information relating to the symbol system(s) and the manner in which they are being used. I invite readers who are endeavouring to keep such records to write and share their procedures and their findings.

### Dignity

We can all agree that dignity is the right of every individual. Yet how much attention is given to the dignity of augmentative communicators as their communication boards are being constructed or updated? Do the symbols portray the level of maturity and cognitive capability of the individual?

Is the display maintained in a condition and with a vocabulary that the individual can feel proud of? Do the symbols allow the individual to communicate in a manner that is appropriate to his or her role or status in a variety of situations? I have to ask these questions frequently with regard to the communication boards of augmentative communicators I know. I am very aware of how often I and others fall short in our assistance and how time constraints and practical considerations interfere with *dignity* being facilitated through communication boards!

### Opportunity

The individual's symbol system - be it based upon graphics (aided) or signing (unaided) - should offer as many of the opportunities provided by speech as possible. Does the format of the individual's keyboard or communication board provide opportunities that allow the individual to demonstrate his or her interests, competencies and understandings? Does the graphic system chosen offer opportunities for language and cognitive learnings? If so, how does the structure of the system support or impede language and cognitive development? Do the symbols provide the kinds of experience that will support the development of literacy? Are there opportunities for the individual to generate new vocabulary items? Does the vocabulary provide the opportunity to fully participate in any chosen activity?

Dr. Kirby quoted Louis Pasteur, "Chance favours the prepared mind". What a valuable thought to relate to symbols! How are individuals' symbol systems preparing their minds to be ready for the chances that will occur in their lives - the opportunities for socializing, for receiving an education, for developing vocational and avocational skills, for gaining or regaining a contributing role in the community? We are only now framing the questions. In future issues we will

pursue them and hopefully provide beginning answers.

### For the Future

My goal in SymbolTalk is to look at symbols carefully enough and with sufficient knowledge that we will become more discriminating and better equipped to compare and evaluate different symbol sets and systems. Lest we become too narrow in our viewing, I offer one further insight from Dr. Kirby. As a good Scotsman, he used the tartan as a reminder that wholes are greater than the sum of their parts. As we *communicate together* about symbols through the coming years, the tartan will be *our* symbol, signalling that any specific feature we examine needs to be evaluated as to its relationship within the *whole* symbolic system as used by the individual - and within the *whole* life context of the individual.

### References:

Beukelman, D.R. (1991). Magic and cost of communicative competence. Augmentative and Alternative Communication, 7(1), 2-10.

Light, J., & Lindsay, P. (1991). Cognitive Science and Augmentative and Alternative Communication. Augmentative and Alternative Communication, 7 (3).

McNaughton, S. (1990). Gaining the most from AAC's growing years. Augmentative and Alternative Communication, 6(1), 2-14.

<sup>1</sup> Information regarding BlissWorld is available from Blissymbolics Communication International, 250 Ferrand Drive, Suite 200, Don Mills, Ont. Canada Canada, M3C 3P2.



## WHAT'S NEW

ROB HAAF &  
COLLEEN MCGAFFEY

"What's New" will present an overview of new developments in AAC hardware, software and resource materials. Listings are current as of three months before publication. Manufacturers and suppliers are listed alphabetically below the product listings.

### Books

*Causes and Effects in Communication and Language Intervention*, edited by Steven F. Warren and Joe Reichle. An overview of research findings and current developments in areas of communication intervention (parent-focused language intervention, beginning augmentative communication systems, communicative competence, measuring conversational language, evaluating outcomes). Available from **Brookes Publishing Co.**

*Educating Children with Multiple Disabilities*, by Fred P. Orelve & Dick Sobsey. A newly updated, practically-oriented text providing guides to assessment, health care, handling and positioning, instructional adaptations and other areas from a trans-disciplinary perspective. Available from **Brookes Publishing Co.**

*Speech Synthesis: Technology for Disabled People*, by Alistair D.N. Edwards. Provides an overview of modern speech technology, and computer interfacing issues. Also provides specific descriptions (and illustrations) of widely used synthetic speech devices, along with case studies illustrating applications of various products. Available from **Brookes Publishing Co.**

### Graphics

*Picture Communication Symbols - Book III* will be available from **Mayer-Johnson** in Fall 1991. The expanded vocabulary is scheduled to include a wider range of medical and health symbols.

*Sigsymbols*, American Edition, (1990) by Ailsa Cregan and Lyle L. Lloyd is available from **Don Johnson Developmental Equipment Inc.** Contains complete listing of Sigsymbols, criteria for designing Sigsymbols, suggestions for learning activities and Sigsymbol games and activities.

### Hardware

Prentke-Romich Co. plans to introduce the *Wireless Headmaster* by late Summer 1991. The Headmaster is a mouse emulation device using head movements to position a mouse pointer and a "sip and puff" switch to click. Comes with an on-screen keyboard for typing. Headmaster models are available for Macintosh and IBM PC computers. The wireless model can be mounted on a wheelchair, and does not require direct connection to the computer. For more information contact **Prentke-Romich**.

### Software

The Blissymbolics Communication Institute (BCI) is now offering the latest version of the *AccessBliss* display creation program for the Macintosh. Version 1.3 includes improved searching abilities, and the ability to easily paste symbols in column format. For more information, contact **Blissymbolics Communication International (BCI)**

Mayer-Johnson Co. now offers an upgrade to the *Boardmaker* display creation program for the Macintosh. The package includes new pre-made

grids for a range of voice output aids, and a new desk accessory that makes symbol retrieval faster and easier. For more information contact **Mayer-Johnson**.

*A Guide to Using AccessBliss for Symbol Creation* is a manual soon to be available from **BCI**. The manual outlines procedures for using Macintosh drawing and painting programs to create modified symbols (such as Picture Your Bliss), and working with both AccessBliss and Boardmaker. For more information contact **Blissymbolics Communication International (BCI)**.

*Interaction Games II*, by R. J. Cooper, offers a new set of two-player games designed for single switch users. Games include Horse Race and Mountain Climber. For Apple II computers. Available from **Don Johnston Developmental Equipment**.

*Talking Symbols* is a software package from Mayer-Johnson that allows you to create talking, multi-level symbol displays on the Macintosh screen. Users can access the Boardmaker library to create PCS symbol overlays and interactive lessons with voice output. Input methods include direct selection (keyboard, mouse, trackball or joystick) and single-switch scanning. *Talking Symbols* uses MacinTalk and is also compatible with a DECTalk speech synthesizer. A demo disk is available from **Mayer-Johnson**.

*To Pair* is a program developed at Bloorview Children's Hospital, Toronto, Canada for Apple II computers. It allows single-switch users to perform a variety of identification and matching tasks with Blissymbols and written words. The program is now available through **Blissymbolics Communication International**.



## Voice Output Systems

**Adaptive Communication Systems (ACS)** has announced the release of the DynaVox for September 1991. This portable unit features a dynamic display, with full customization of the symbol displays on a back-lit LED screen; a stored library of over 800 picture symbols created by Faith Carlson; multiple input modes, including direct selection, one and two-switch scanning; DECTalk speech; and dynamic features such as animated verb symbols. Replaceable modules will eventually feature applications such as abbreviation expansion. For more information contact **ACS** (or **TYKRIS, Inc.**, in Canada).

ACS has also announced the release of the MultiVoice, the first portable (4 lb.) speech synthesizer featuring DECTalk speech. DECTalk is considered to be one of the most intelligible synthetic speech devices available, and offers 10 different voices (including male and female, adult and child voices), and improved singing abilities. Contact ACS for details.

**Phonic Ear, Inc.** is releasing the EZ Viewer for the VOIS 160 voice output aid. EZ Viewer is a 40-character, 16-line backlit LCD display. It can be attached directly to the 160 or placed on a table, computer-style. Requires P.A.L.L.S. software version 3.0 or later.

Phonic Ear, Inc. has also introduced the VoisShapes software package for the VOIS 160. VoisShapes is a vocabulary representation system based on American Sign Language, where words and phrases are generated using a maximum of three keystrokes representing body location, handshape and movement. VoisShapes can be installed in existing VOIS 160 units. For brochures and more information contact **Phonic Ear, Ltd.**

**Prentke-Romich, Co.**, now offers DECTalk speech with the Light Talker TM and Touch Talker TM. DECTalk is available on all new PRC units, and Touch Talkers or Light Talkers with ECHO or SmoothTalker can be upgraded to DECTalk by trained service personnel, or by sending the unit to Prentke-Romich for upgrading.

### Suppliers

Adaptive Communication Systems,  
PO Box 12440  
Pittsburgh, PA 15231  
Phone: 1-800-247-3433  
FAX: (412) 264-1143

Blissymbolics Comm. Int. (BCI)  
250 Ferrand Drive, Suite 200  
Don Mills, Ontario Canada M3C 3P2  
Phone: (416) 421-8377  
FAX: (416) 696-1035

Brookes Publishing Co.  
P. O. Box 10624  
Baltimore, MD 21285-9945

Don Johnston Developmental  
Equipment, Inc.  
P.O. Box 639 - 1000 N. Rand Road,

Building 115, Wauconda, IL 60084  
Phone: (708) 526-2682;  
1-800-999-4660 (U.S. & Canada)

Mayer-Johnson Co.  
P.O. Box 1579  
Solana Beach, CA 92075-1579  
Phone: (619) 481-2489  
FAX: (619) 259-5726

Phonic Ear, Inc. (USA)  
3880 Cypress Drive  
Petaluma, CA. USA 94954-7600  
PHONE: (707) 769-1110  
FAX: (707) 769-9624

Phonic Ear, Ltd (Canada)  
7475 Kimbel Street,  
Mississauga, Ont. L5S 1E7  
PHONE: (416) 677-3231;  
1-800-263-8700  
FAX: (416) 677-7760

Prentke-Romich Co.  
1022 Heyl Road,  
Wooster, Ohio 44691  
Phone: (216) 262-1984;  
1-800-253-1984 (Canada)

TYKRIS, Inc.  
421 Nugget Avenue, Unit #5  
Scarborough, Ont., Canada M1S 4L8  
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## Call Centre Communication Camp

PETER LINDSAY

*We are delighted to have a letter from the Call Centre in Scotland as the first letter in the Readers Write section of our inaugural issue. Thank you Sally and Amy. It sounds like the camp was a great success for all. It is very gratifying to hear that the campers enjoyed reading material from **Communicating Together** because that is precisely whom we hope will find this magazine interesting. Kari has another brief poem in this issue and we look forward to including more poetry in future issues. We hope others around the world will respond to the challenge from Scotland to tell us about their successful "camps" or just to share with us their interesting experiences communicating together.*

## Call Centre Communication Camp

We are writing to you on behalf of a group of friends and colleagues here in Scotland, UK. Recently we had our second annual week long residential 'Communication Camp 1991' near Edinburgh, for adults who use Minspeak-based augmentative communication systems. There were 15 adult AAC users there - all with Touch Talkers or Light Talkers and some also with their Bliss charts and books - along with 25 volunteer helpers - speech therapists, care workers, engineers, teachers, and others. Now, the thing is, unlike in North America, here in Scotland Summer Camp is not a tradition, but quite a new and revolutionary idea. Where did we get the idea? Well, we'd like you and your readers to know that we got the idea first of all from an article by Andrew Murphy in **Communicating To-**

**gether**. He wrote about how he was worried in case he could not find anyone to understand his communication attempts, when he went to adventure camp; we thought - what about making communication itself the adventure of camp?

During our camp week here we all did many, many things! The overall aim was fun, and the development of functional communication skills. We worked very hard on language and communication skills every morning (and much of the afternoon, evening, and late into the night, too); we did drama; we went on outings to the pub, cinema, shops, bowling, zoo etc; we played lots of daft games and tricks, we cracked lots of jokes, and sang lots of electronic songs too! Perhaps most important of all, people for once had time to really talk and listen; communication was Number One on the agenda. Everyone was expected to produce the very best they could with their communication system - and everybody did! And everybody went home exhausted, but filled up with fun and achievement.

One of the things the group particularly enjoyed in the morning 'Communication Group' work was readings aloud from poems and articles written and published by other non-speaking people. It was a 'first' for many of the people there. It turned out that very few of the AAC users who were at Camp did any reading for themselves, for one reason or another. And none of us had had the luxury of being *read aloud to* for many many years, since being kids. We just loved it! Where did we find the articles to read out? Well - just about **all** of the best articles we could find to read out were from **Communicating Together**.

We found out that lots of people especially liked hearing poems read aloud. (Some people had hardly ever heard a poem before - maybe poems

were not considered 'suitable' material in special schools for children who cannot speak). We all liked *your* poems, Kari! We were happy with the idea that true and great and beautiful thoughts do not necessarily need long miles of fancy language for their expression - they can be expressed with short and simple words, so long as they are *the right words, in the right place, at the right time*. This idea inspired us in our communication skills work, all week.

The group also liked to hear stories from people who had found funny but effective ways of speaking up for themselves, when in danger of being 'squashed' by the power of the speaking, walking world. As we read aloud, and looked around the room, there was always someone nodding or shouting out that the same thing had happened to them, at some point! This experience may have helped people to realise that they too might have something to write about, and we discussed how there are new technical developments which will allow Touch Talker and Light Talker users to write from their own overlays on their devices, even when their actual spelling is not so hot!

So we are sending a big '*Thank You*' from Scotland to you and your team of AAC user colleagues for sharing such good ideas, and for writing the works that have so delighted and inspired us, your AAC friends here at 'CALL Centre Communication Camp Scotland 1991'. We hope you will publish this letter in **Communicating Together** to let all your writer colleagues know how much we appreciate their work, and to inspire them to keep on writing more! **Communicating Together** is great!

Sally Millar Amy Joss



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